

NUMBER XXVII NOVEMBER 2005

# BREAKING GROUND

THE NEWSLETTER OF THE TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES



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Cover photo by Lynette Swinford

## CONTACT INFORMATION



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# WHOSE LIFE IS IT ANYWAY? MY EXPERIENCE OF TRYING TO GET PEOPLE TO LISTEN TO ME

## BY LORRI MABRY

My name is Lorrinda Kay Mabry. I like to be called Lorri for short. I was born at St. Thomas Hospital on August 31, 1965. When I was five days old, my mom and dad picked me up because I'm adopted.

I was born with a condition called cerebral palsy. Most people think it's a disease, but it's not. Something damaged my brain but I am not sick. I just need some help to do some things. I can't walk or talk but I use an electric wheelchair to get around and I talk with a device which sounds like a female voice.

I didn't have this equipment during the first half of my life. My mom first noticed something was wrong when I was old enough to sit by myself but I never tried. The doctors told Mom I was just slower to develop than other children my age.

My mother waited for me to do things like other children, but I never did. So a friend of my mother's got me in the clinic at Vanderbilt Hospital. They ran tests on me. At eighteen months I was diagnosed with cerebral palsy. The doctors told my parents that I was "mentally retarded"—that was what it was called back then. I think that was because I couldn't move the blocks of the IQ test because of my hands.

On one of my visits to the doctor at the Vanderbilt Cerebral Palsy Clinic, Dr. Hillman told a joke and I laughed. He told my parents that I was smart.

My mom and dad read books to me when I was young. When we went to the store, I asked for a book instead of a toy. Before I was three, I started attending a preschool program for children with communication difficulties. This gave me other children to play with, and it gave my parents other parents to talk to about my condition. I had three close friends who I visited. I had no way of communicating back then, except

pointing, laughing or crying.

In my preschool, they gave me some reading books with pictures instead of words to teach me to read symbols so I could use a communication board with symbols later. I didn't want to use the picture books. I wanted regular books to read. I learned my alphabet and my numbers from watching Sesame Street and other PBS shows before I started school. When I was school age, my parents were told that I had to go to a special education school, because this was in the early 1970s, and nobody had thought of the IDEA (Individual with Disabilities Education Act) yet. I had to be tested to get into school, and had to have an IQ of 70. I passed that with flying colors.

During my first year of school, I finished readers in a few months when it would take the rest of the students a year. I went to the Kennedy Center to figure out how I could do my work in school. They figured out I could type with one finger. They taught me to type by telling me they'd give me an M & M if I typed it on the typewriter, so I did it about ten times a session!

I loved school for the most part, but I felt isolated, because I didn't have my typewriter to join in the conversation. In special education, they taught many skills over and over for several years. Some of us were bored to tears.

Especially when Sesame Street time came around and the teachers put us in front of the television, expecting us to stay awake through the 500 times we saw it.

I think my teachers did the best

they could with many levels of learning. They put us in classes by our ages instead of what grade level we were on. The school board didn't purchase regular books for us. Our teachers had to order our books themselves, sometimes with their own money.

When I had my first hip surgery, I had to stay on my back for three months in a body cast from the waist down. I couldn't type when I was lying down, so one of my adult friends figured out that with one of my toys with magnet letters I could pull down the letters to spell the words. Later, my mom figured out she could put the letters on a piece of cardboard, and I could point to them to spell the words out. This became my primary means of communication until I was twenty-six! It was easier to carry it around but some people didn't have the patience and some people couldn't follow me. But it was better than nothing.

Back to the school situation. I think my first year at Harris-Hillman School was a waste of everyone's time, because there were too many levels to teach to. So the next year we were split up by our abilities. By the next year we were mainstreamed. Still, they had trouble finding a school for the older group that I was in, because most of the schools in Nashville were old, and not accessible to wheelchairs. They found one but they couldn't fix an emergency exit

*Continued on page 12*



LORRI MABRY WITH HER TALKING KEYBOARD. PHOTO CREDIT: LYNETTE SWINFORD

# ALLIANCE FOR FULL PARTICIPATION

## BY ELISE MCMILLAN

*More than 40 Tennesseans from across the State attended the national Alliance for Full Participation held September 22 and 23 in Washington, DC. Although the two days of meetings have concluded, plans continue at both the state and national levels to advance the work begun by the group.*

The September meeting of more than 2,400 people was the result of 18 months of planning by 11 national organizations working together to serve as a catalyst for change and as a stimulus for partnership in the area of disabilities. In the midst of urgent natural disasters, individuals who live with lifelong disabilities, their family members, and the people who work alongside them, came together to participate in this groundbreaking event.

Prior to the meeting, each state was asked to form a state team and develop a priority plan. Tennessee's team came together under the leadership provided by Wanda Willis, executive director of the Tennessee Council on Developmental Disabilities. More than 26 Tennessee organizations participated in a series of meetings to accomplish this process.

The Tennessee team developed priorities in each of three areas:

- BUILDING COMMUNITIES THAT WELCOME AND SUPPORT PEOPLE WITH DISABILITIES;
- UPGRADING THE WORKFORCE THAT PROVIDES SUPPORTS AND SERVICES TO PEOPLE WITH DISABILITIES AND ESTABLISHING PERFORMANCE EXPECTATIONS; AND
- SUPPORTING THE NEXT GENERATIONS OF INDIVIDUAL, ORGANIZATIONAL, ADVOCACY AND COMMUNITY LEADERSHIP.

A poster with an overview was presented by the Tennessee team in Washington on September 23rd. A reduced copy of the poster, which includes specific priorities in the three areas outlined plus a listing of the agen-

cies constituting the State team, is available from the Council upon request.

Keynote speakers for the Washington conference included:

Roger Nierenberg, conductor of the Stamford Symphony Orchestra. Mr. Nierenberg used the collaborative nature of music as his platform to help attendees understand leadership styles and to help develop high performance teams.

Martin Luther King III, president and CEO of the King Center. Mr. King talked about continuing his father's quest for equality and justice for all.

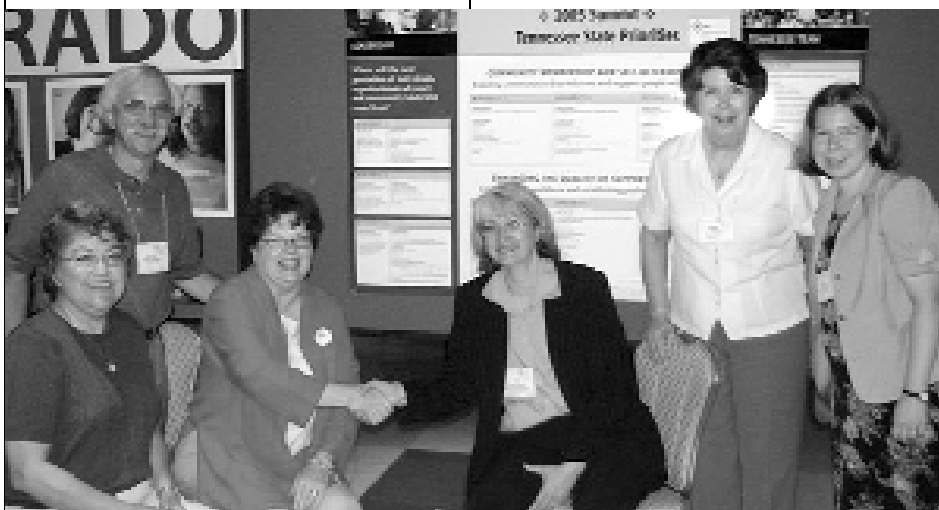
Frank Sesno, special correspondent for CNN and professor of public policy and communication at George Mason University. Dr. Sesno, who has an adult sister with Down syndrome, hosted an interactive Town Hall Meeting. The session included many individuals with dis-

abilities and others on key topics such as housing, employment, and education.

Members of the audience voted on key issues in these areas.

The conference also offered breakout presentations with panelists from across the country. Many Tennesseans, including Fred Palmer, Andrea Cooper, Leanne Boyce, Gatha Logan, Elise McMillan, Will McMillan and Debra Martin-Lueking, were invited participants.

Following the two days of meetings, representatives of the 11 founding groups, which are the American Association on Mental Retardation, the American Network of Community Options and Resources, The Arc of the US, the Association of University Centers on Disabilities, the Council on Quality and Leadership, the National Alliance for Direct Support Professionals, Disability Rights, the National Association of Councils on Developmental Disabilities, the National



A FEW OF THE MEMBERS OF THE TENNESSEE DELEGATION TO THE AFP CONFERENCE. SEATED L TO R: SHIRLEY SHEA (EXECUTIVE DIRECTOR, DISABILITY LAW & ADVOCACY CENTER OF TENNESSEE), LAUREL RYAN (FAMILY SUPPORT COORDINATOR, BOLING CENTER FOR DEVELOPMENTAL DISABILITIES), AND ELISE MCMILLAN. STANDING L TO R: DON REDDEN (DIRECTOR, DEVELOPMENTAL SERVICES OF DICKSON COUNTY), RUTH ROBERTS (INTERDISCIPLINARY TRAINING COORDINATOR, BOLING CENTER FOR DEVELOPEMENTAL DISABILITIES), AND SUSAN NEELY-BARNES (UNIVERSITY OF TENNESSEE HEALTH SCIENCE CENTER, COLLEGE OF SOCIAL WORK). PHOTO CREDIT: CRYSTAL PARISEAU

Association of State Directors of Developmental Disabilities Services, United Cerebral Palsy, and Self-Advocates Becoming Empowered, developed the following highlights.

### NATIONAL PRIORITIES

- We are Americans too! We want to be included in all communities in our great nation and to have all the rights and responsibilities of full citizenship. We need to be safe and free at the same time. We know how to do this. Few American communities are listening.
- We belong in schools, neighborhoods, businesses, government, and churches, synagogues and mosques.
- We do not belong in segregated institutions, sheltered workshops, special schools or nursing homes. Those places must close, to be replaced by houses, apartments and condos in regular neighborhoods, and neighborhood schools that have the tools they need to include us. We can all live, work and learn in the community.
- We can work in worthwhile jobs. We know how to help each other do this. It is being done in some places, just not all places. We hope to be welcomed to work for the American dream alongside other

Americans.

- For states that still fund public and private institutions, we want to see a plan to close them over the next few years, and people with lifelong disabilities helped to live in communities, in regular houses and regular neighborhoods. Starting today we expect all states to stop placing children in institutions and segregated residential schools.
- Families with sons and daughters with lifelong disabilities often need some support to have equal access to full and rich family lives. Having a child (who may be an adult now) with a disability must not force a family into poverty or constant, lifelong worry. While some have support to lead decent lives, others have not and are isolated and feel abandoned by America. Everyone who needs it must get the support they need.
- The term *mental retardation* has become hurtful. Stop using it! Words hurt and labels limit human potential. It is un-American. Try calling people by their name.
- Public funds expended on behalf of people with developmental disabilities must be under their control and direction and, for children and others who need it, their families and trusted friends.

- People who have chosen to work in this field directly with people with developmental disabilities should be paid a decent wage with benefits; they should not have to work two or three jobs just to support their families. This is important work that must be respected.
- Medicaid is the vital lifeline for people with developmental disabilities. Medicaid reform must protect access to this program, promote inclusion for people in their communities and empower citizens to control the funds spent on their behalf.

Teams are working in each state to implement the vision and goals developed by the state teams and during the conference. For more information about the national activities, visit [www.AllianceForFullParticipation.org](http://www.AllianceForFullParticipation.org).

Meetings in Tennessee will continue with a gathering planned in early November.

For more information in Tennessee, contact Wanda Willis at the Tennessee Council on Developmental Disabilities (615) 532-6615 or [wanda.willis@state.tn.us](mailto:wanda.willis@state.tn.us).

*Elise McMillan is director of community outreach for the Vanderbilt Kennedy Center for Research on Human*

## INTRODUCING MILDRED SPARKMAN



Hello, my name is Mildred Sparkman. As of May, 2005, I am the Council's Administrative Secretary. I am a native Nashvillian. I love Nashville, and the people who make up this great community, and I am so excited about working with the Council. I look forward to this opportunity to serve in God's beautiful rich flower garden.

I have been married 22 years and have two children, a daughter, 19, and a son, 17. I especially enjoy taking care of my family and sharing fun activities like attending Pearl Cohn "Firebirds" football games to support my son's interest in participating in competitive sports. My other interests include gardening, swimming, singing, and taking brisk walks. I also like to travel and enjoy working with my church family on community projects.

# ACCENTUATE THE POSITIVE – FOR ALL STUDENTS

## By Jan Rosemergy

*When IDEA (Individuals with Disabilities Education Act) was reauthorized in 1997, the law required all schools to address Positive Behavior Support (PBS). “Positive Behavior Support teaches students the social skills and behaviors they need to develop socially and do better in school,” explained Kathleen Lane. Dr. Lane is assistant professor of special education at Peabody College, Vanderbilt University, and is a researcher in the Vanderbilt Kennedy Center for Research on Human Development.*

Dr. Lane is experienced in working with school teams to develop and implement three-tiered PBS plans unique to their own schools. She recently completed a three-year project to implement PBS at the high school level. The project was funded by the Office of Special Education Programs, U. S. Department of Education. Dr. Lane also leads the Vanderbilt Kennedy Center’s Britt Henderson Training Series for Educators, where in recent years teams from public and private Middle Tennessee schools have learned how to make PBS work for their schools and students.

Fairview Middle School began using PBS during the 2004-05 school year after their school team took part in the Henderson training on PBS. The team was made up of their assistant principal, a general and special education teacher, a parent, and a student.

“One of the roles of an assistant principal is to hand out punishments for bad behavior,” said Gary Shrader, assistant principal of Fairview Middle School. “That gets tiresome and as a person who likes to be positive, I saw the advantage of a school-wide PBS plan.”

Both Dr. Lane and Mr. Shrader emphasize that PBS is all about having consistent

school-wide expectations for behavior, providing students with opportunities to practice these expectations, and rewarding good behavior, thereby helping to prevent undesirable behavior.

### PRIMARY PREVENTION

“PBS is a three-tiered model of support designed to create a climate shift in the school,” Dr. Lane said. “It’s proactive in nature. It’s based on providing students with the level of support necessary for them to be successful in the general education setting to the maximum extent possible.”



The first or Primary Prevention level is for every student in the school. With input from everyone at the school, a team clarifies what behavior is expected of all children. “You can teach every student what is expected, give them lots of opportunities to practice it, and give reinforcements for meeting those expectations,” explained Dr. Lane. Behavior is related to specific settings; for example, classrooms, hallways, cafeteria, library, or playground. Once those expectations have been made clear to staff, students, and parents, “everyone is on the same page so that students receive a consistent message,” Dr. Lane continued.

“Being respectful” is at the core of Fairview Middle School’s Primary plan. “We knew that we had to educate students about what that meant,” said Mr. Shrader. “In implementing our plan, we were very deliberate about not putting more onto teachers. We’re lucky to have a creative drama

teacher who makes videos, so that each morning we can show students positive behavior. Although most of the videos focus on the positive, some address a particular problem that we may be experiencing, for example, bullying or absenteeism.”

Like many schools, the Fairview staff chose “tickets” to reward positive behavior. Students with a specified number of tickets are admitted to a PBS Assembly, where there are drawings to win prizes. A committee works on prize donations, and the Parent Teacher Organization helps as well.

### SECONDARY PREVENTION

Primary Prevention meets the needs of about 80% of students, according to Dr. Lane. The next level is Secondary Prevention, which is designed to reduce current cases of problem behavior. “These students need more explicit instruction to meet expectations, and we need to respond to specific behavioral concerns,” Dr. Lane said. “We use school-wide data to identify children who are having problems like aggression, noncompliance, poor conflict-resolution skills, or poor study skills. Then the school provides more focused interventions for this group of children so that they can be better supported in the general education setting.”

Fairview Middle School’s Secondary Prevention plan includes teaching conflict resolution skills and study skills. They are implementing this plan now and will use data collected to decide which of these approaches, or combinations of elements from these approaches, are most effective. Their criteria for referral to Secondary Prevention Level are behavioral (office referrals) and academic (grade point average). Dr. Lane indicated that of the 20% of children whose needs are not met by the Primary Level, the needs of 8% to 12% will be met by the Secondary plan.

## TERTIARY PREVENTION

The Tertiary Prevention plan aims at reducing the intensity and severity of current cases of problem behavior. Fairview Middle School is in the process of developing its Tertiary plan. "These are the most individualized interventions possible," Dr. Lane explained. "Based on a functional assessment of student behavior, a school team designs, implements, and evaluates an individualized intervention."

Dr. Lane stressed that PBS matches the level of intensity for service based on student need, all within the context of the general education model. "Students are getting all this support from and by the general education system to support learners in a variety of circumstances." PBS has been well-studied at the elementary level, with less research at the middle school level and even fewer studies at the high school level. The PBS approach is increasingly in wide use across the country, according to Dr. Lane.

PBS is one way schools are addressing the behavioral component of IDEA '97. Most

educators respond well to problem behaviors when they occur, but they have less training in how to prevent them. PBS leads to fewer problem behaviors to respond to. For example, at Fairview High School, when the number of office referrals during their first quarter of implementation of a school-wide PBS Primary Prevention plan was compared to the number of office referrals made during the first quarter of the previous school year, discipline referrals were cut almost in half.

Mr. Shrader summarizes their experience at Fairview Middle School: "PBS has been effective for all students. It's simple. Students with cognitive disabilities can understand it, too. In fact, some of our students with the most severe disabilities have won some of the bigger prizes. PBS has gotten everyone to be more positive. The whole atmosphere of the school is positive."

*Jan Rosemergy is director of communications at the Vanderbilt Kennedy Center for Research on Human Development, a national center for research on development and disabilities.*

## HEALTH TOPICS LIBRARY ON-LINE

The Junior League Family Resource Center at Monroe Carell Jr. Children's Hospital at Vanderbilt (VCH) continues to build a library of valuable resources on pediatric health conditions. Currently, nearly two dozen health topics are available online, including topics such as stuttering and communication disorders and autism spectrum disorders. Each topic includes an annotated list of books, videos, and file materials housed at the Family Resource Center. The information included in the Health Library is reviewed by a family member and an expert at Vanderbilt. Each topic also features a host of recommended community resources and Web sites. Visit <http://www.vanderbiltchildrens.com/healthlibrary>.

Health Tips for parents is a new feature on the VCH Web Home Page. Each is reviewed by VCH experts. A new tip appears on the Web site each month. See the Family Resources section for all Health Tips.

The Family Resource Center contains resources for families on more than 1,000 other health conditions, including material specifically for children and teens. For more information on the Family Resource Center and the Health Library, visit <http://www.vanderbiltchildrens.com/frc> or telephone (615) 936-2558 or (800) 288-0391. You may also send an e-mail to [family.frc@vanderbilt.edu](mailto:family.frc@vanderbilt.edu).



KATHLEEN LANE (CENTER) AT THE VANDERBILT KENNEDY CENTER'S 2005-06 BRITT HENDERSON TRAINING SERIES FOR EDUCATORS OPENING SESSION FOR PBS TRAINING, WITH PEABODY SPECIAL EDUCATION MASTER'S STUDENTS JESSICA WEISENBACH (LEFT) AND MEGAN MERWIN (RIGHT) WHO SUPPORT SCHOOL TEAMS IMPLEMENTING PBS.  
PHOTO CREDIT: MELANIE BRIDGES

# LARGEST PARTNERS IN POLICYMAKING™ CLASS EVER HITS THE GROUND RUNNING!

While a number of Partners in Policymaking™ programs around the country are losing funding or suffering from low numbers of applicants, Partners in Tennessee is enjoying its largest class since it began in 1993, and the continued enthusiastic support of the Tennessee Council on Developmental Disabilities.

Twenty-nine individuals, divided almost evenly between adults with disabilities and family members of persons with disabilities, gathered at the Nashville Airport Marriott September 9 and 10 to hear presentations on the History of the Disability Movement and People First Language from national presenters Robert Watson and Liz Weintraub, and local presenters, Gina Lynch—a 2003-04 Partners graduate, and Partners director, Ned Andrew Solomon.

The program is thrilled to have its first Youth Leadership Forum graduate join the Partners ranks...Melissa Allen from Memphis!

Over the course of six more weekend sessions, the 2005-06 Partners will learn about:

- Assistive technology
- Inclusive education

- Building communities
- Supported living/home of your own initiatives
- Supported, competitive and self-employment
- Service coordination
- Strategies for system change, including public speaking, letter writing, preparing testimony, working with legislators and the media, and conducting effective meetings

We are pleased to welcome the following individuals into the Tennessee Partners network:

MERRY ADAMS, SMYRNA  
 MELISSA ALLEN, MEMPHIS  
 ADAM BALLARD, LAKE LAND  
 BRUCE BENTLEY, NASHVILLE  
 ANGELA BRAACH, MURFREESBORO  
 DEBORAH BUTLER, KNOXVILLE  
 SUZETTE BYRD, MARYVILLE  
 JENNY CATES, COLUMBIA  
 KIRK DAVIS, NASHVILLE  
 GWEN DYER, MURFREESBORO  
 CAROL FRANCISCO, NASHVILLE  
 MICHAEL FREEMAN, ARLINGTON  
 STACE HARRIS, CORDOVA  
 PAM HEROLD, HENDERSONVILLE

ROBIN LINER, HARRISON  
 TYSON MCCLANAHAN, COOKEVILLE  
 KAREN MEVIS, KINGSTON SPRINGS  
 JOHN PIVER, JOHNSON CITY  
 RICKY POWELL, NASHVILLE  
 JAMES REEVES, SMYRNA  
 ANITA ROBINSON, MEMPHIS  
 LAUREL RYAN, COLLIERVILLE  
 LORI SIEGAL, GERMANTOWN  
 AMY WALLACE, NASHVILLE  
 MARANDA WATTERS, HILLSBORO  
 SUZETTE WEBSTER, NASHVILLE  
 PERRY WEEMS, GREENEVILLE  
 WILLIE WELLS, CORDOVA  
 SHARA WINTON, MURFREESBORO

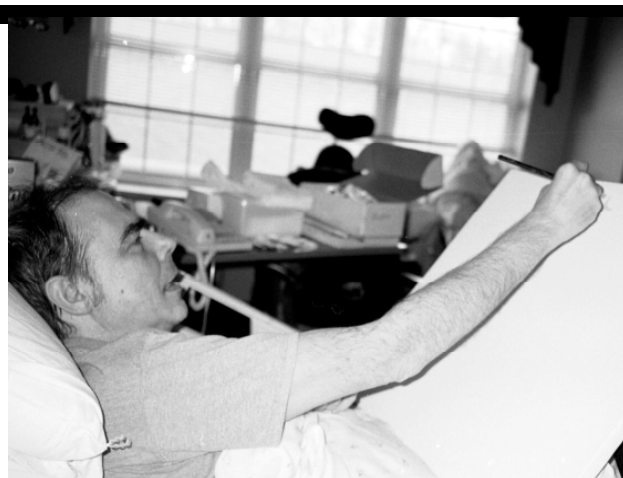
Applications to the Partners in Policymaking™ program are distributed and accepted year round. The deadline for the 2006-07 Partners class is April 1, 2006. For an application or more information, please contact:

Ned Andrew Solomon  
 Tennessee Council on  
 Developmental Disabilities  
 Andrew Jackson Building, Suite 1310  
 500 Deaderick Street  
 Nashville, TN 37243-0228  
 615-532-6556  
 ned.solomon@state.tn.us

## CONDOLENCES: RON MILLER

We were saddened to hear of the death of Ron Miller as we were going to press with the Arts Issue of *Breaking Ground*. Mr. Miller, 53, a resident of NHC Place in Cool Springs, had multiple sclerosis for more than 30 years. The finished abstract painting we published in the Arts Issue, shown here in progress, was the first painting that he had shared publicly. Our condolences go out to Mr. Miller's family and friends.

PHOTO CREDIT: MAYRA MORALES



# MEDICARE'S NEW COVERAGE FOR PRESCRIPTION DRUGS

**Starting January 1, 2006, Medicare will be offering insurance coverage for prescription drugs.**

**Everyone with Medicare is eligible for this coverage, regardless of income level, resources, pre-existing conditions or current prescription expenses. If you have Medicare and have a limited income and resources, you may qualify for extra help paying for prescription drugs.**

In October, 2005, detailed information from Medicare should have begun arriving in the mail for all people who are currently on Medicare.

If you are a person with both Medicare and Medicaid, your prescription drug coverage is changing also. Starting January 1, 2006, Medicare will pay for your prescription drugs. This means that TennCare (Tennessee's Medicaid program) will STOP paying for prescription drugs after December 31, 2005. TennCare will still pay for your other medical costs.

If you have Medicare and TennCare, you will get help with paying for a drug plan's monthly premium and for the cost of your prescriptions. You will NOT need to apply for this help.

## HOW TO JOIN

Enrollment for the new Medicare prescription drug program begins November 15, 2005. Anyone signing up before December 31, 2005, will have coverage starting on January 1, 2006. Anyone currently on Medicare should have received instructions on how to join in the Medicare & You handbook in October 2005.

If you don't sign up with a plan by May 15, 2006, you may have to pay a penalty. An opportunity to enroll in the program will occur November 15 through December 31 of

each year. For More Information you can call 1-800-MEDICARE (1-800-633-4277). This line is open 24 hours a day, 7 days a week. TTY 1-877-486-2048.

You can also visit Medicare's Web site at [www.medicare.gov](http://www.medicare.gov).

## IMPORTANT DATES for Medicare Prescription Drug Coverage

- **October, 2005** – Information arrives for all current Medicare enrollees
- **November 15, 2005** – First day you can join a plan
- **January 1, 2006** – Coverage begins for those who join by December 31, 2005
- **May 15, 2006** – Last day to join a plan without paying a penalty

In Tennessee, people with Medicare will be able to get prescription drug coverage in January, through their choice of either a newly approved stand-alone prescription drug plan that works with traditional Medicare, or a Medicare Advantage plan that offers drug coverage and other benefits.

Sixteen organizations will offer stand-alone prescription drug plans, including one with a premium of less than \$20 a month. People with Medicare in Tennessee can also get drug coverage with additional benefits and even lower total out-of-pocket costs by enrolling in Medicare Advantage plans. The Medicare Advantage options include one new

statewide PPO plan and, in 2006, three Medicare Advantage organizations will provide prescription drug coverage for no additional cost. "Thanks to the range of options available, everyone in Medicare who lives in Tennessee will be able to choose a prescription drug plan that addresses their individual concerns about cost, coverage and convenience," Health and Human Services Secretary Mike Leavitt said. "For premiums that are in many cases much lower than expected seniors will be able to get Medicare-approved prescription drug coverage that will help protect their health as well as their savings."

Prescription drug coverage will be available to everyone in Medicare, regardless of their income or how they get their Medicare coverage. Extra assistance is available to those with limited incomes and resources. Of the organizations offering drug coverage in Tennessee, eight will have prescription drug plans available with no premium to beneficiaries who qualify for that extra help.

"...CMS [Centers for Medicare & Medicaid Services] notified plans that have met all of Medicare's standards and are approved to compete to provide Medicare prescription drug coverage," said CMS Administrator Mark McClellan. "Plan marketing will begin on schedule on October 1, and as we approach the start of enrollment on November 15, Medicare will work with our partners in Tennessee and around the country to help people with Medicare make their decisions."

All plans approved in Tennessee have met Medicare's requirements for providing access to medically necessary drugs, including formulary standards as well as standards for access to convenient retail pharmacies and to drugs in nursing homes. All plans are required to provide coverage at least as good as Medicare's standard coverage, which pays, on average, 75% of drug costs after a \$250 deductible up to \$2,250 in total drug spending. The coverage also pays approximately 95% after \$3,600 in out-of-pocket costs to protect against very high drug expenses. This means that for a monthly premium that is lower than expected,

Medicare would pay more than half of a typical beneficiary's drug costs, or more than \$1,100.

"As a result of the strong competition in Tennessee, Medicare coverage will include options that cost less and also that provide coverage that goes beyond Medicare's standard benefit," Dr. McClellan said. "With better opportunities to save and to get the coverage that works for you, it's about time to start thinking about how you or someone you care about can take advantage of the new coverage."

To get a fit that works for them, beneficiaries should make a note of any current drug coverage, their prescription drugs and their preferences about pharmacies or additional coverage. Medicare beneficiaries in Tennessee can also get personalized, local assistance by calling the Tennessee Commission on Aging & Disability at 1-877-801-0044.

A map of the prescription drug plan and Medicare Advantage plan regions can be found at <http://www.cms.hhs.gov/medicarereform/mmregions/>.

#### **PRESCRIPTION DRUG PLAN COST ESTIMATOR**

The Medicare Prescription Drug Plan Cost Estimator is available on the Web at [http://www.medicare.gov/medicarereform/MPDP\\_Cost\\_Estimator.asp](http://www.medicare.gov/medicarereform/MPDP_Cost_Estimator.asp).

This tool will provide people considering Medicare prescription drug coverage quick reference information. By entering your monthly drug costs and the state you live in, you will get an estimate of annual savings, if you join a Medicare prescription drug plan.

The calculations are based on the defined standard benefit and the lowest premium amount offered by a plan for a particular region of the country.

## **NEW LAW ASSISTS TENNESSEANS WITH DISABILITIES EMPLOYMENT OPPORTUNITIES ENHANCED**

In an effort to encourage more employers to hire people with disabilities, State Representative Harry Brooks of Knoxville proposed legislation to provide incentives to businesses. In June, Governor Phil Bredesen signed the bill into law. Tennessee employers who hire, work with, train and mentor persons with disabilities who receive State services may receive franchise and excise tax credits - \$5,000 for each new full-time employee and \$2,000 for each new part-time employee.

The credits apply to employers who hire persons served by the Division of Mental Retardation Services, Department of Mental Health and Developmental Disabilities, Department of Health, Division of Rehabilitation Services, Department of Finance and Administration and the Tennessee Committee for the Employment of Persons with Disabilities.

According to a 1998 National Organization on Disability (NOD)/Harris Poll of Americans with disabilities, large gaps exist between adults with disabilities and other adults regarding basic aspects of life. Employment was exposed as the widest chasm, with nearly 70% of individuals with disabilities reporting that they were not employed.

"This is a strong measure which will improve the lives of countless Tennesseans with disabilities," said Division of Mental Retardation Services Deputy Commissioner Stephen H. Norris. "Most persons with disabilities are able to work and are successful in all areas of our economy. Access to jobs affords them the opportunity to realize their dreams and be productive members of their communities."

Representative Brooks initiated discussion on employment incentives three years ago. While the law coming to fruition was a strong bi-partisan effort, it was Representative Brooks and State Senator Jim Bryson who spearheaded the effort.

"I'm pleased to support legislation that will create an environment that improves the lives of our disabled citizens," said Representative Brooks. "I believe our state can be a leader in fostering employment for persons with disabilities. This is a great step in that direction."

"This program creates a win-win situation," said Senator Bryson. "It elevates self-worth and self-sufficiency; helping persons achieve life goals. It is also economically advantageous as there is relief from services, saving taxpayers money."

# NEWS FROM PATHFINDER By Melissa Fortson

## HURRICANE KATRINA RESOURCES AT [WWW.FAMILYPATHFINDER.ORG](http://WWW.FAMILYPATHFINDER.ORG)

In the wake of Hurricane Katrina, many people with disabilities were not able to leave the Gulf Coast and are still being affected by power outages. Some are scattered and still unaccounted for, and others may be cut off from needed supports and services—for example, Katrina devastated the local chapter of United Cerebral Palsy in New Orleans, virtually ceasing services to many in need of 24-hour supports. Here in Tennessee, where emergency management officials estimate the total number of evacuees to be approximately 20,000, Tennessee Disability Pathfinder has developed a collection of resources to help them at [www.familypathfinder.org](http://www.familypathfinder.org).

"Pathfinder created this Web-based collection of resources because of evacuees who have contacted us needing services," said Carole Moore-Slater, Pathfinder director. "Pathfinder can provide evacuees with information they will need during their time in Tennessee, from where to find specialized equipment, such as wheelchairs, to what kinds of adult day services are available and how to enroll their children in special education programs."

By going to [www.familypathfinder.org](http://www.familypathfinder.org) and clicking on "Hurricane Resources," users can access information that includes emergency management agencies and education, employment, equipment,

financial assistance, health care, insurance, long-term care, shelter, social security disability, transportation and more. Pathfinder's Hurricane Resources page is updated frequently, and additions, corrections, or suggestions may be sent to [tnpathfinder@vanderbilt.edu](mailto:tnpathfinder@vanderbilt.edu). Tennessee Disability Pathfinder Staff is also available to provide telephone assistance (see "For Further Information" below).

## HEALTH CARE SERVICES: THE PATHFINDER CONNECTION

Due to the recent changes in TennCare, a health insurance program for certain people who live in Tennessee, many people are currently struggling as they face the reduction or loss of their health insurance coverage. Tennessee Disability Pathfinder can help TennCare disenrollees and others without health insurance by connecting them with helping resources. Some of these helping connections include:

- Low-cost primary care clinics
- Local health departments
- Programs that provide medical, dental, mental health and substance abuse services for uninsured persons
- TennCare advocacy
- Transportation to medical services
- Prescription assistance programs
- Insurance assistance programs

To be connected to a resource in your area, contact Tennessee Disability Pathfinder (see "For Further Information" below). Users may also search for Health Care Services using the Pathfinder database at [www.familypathfinder.org](http://www.familypathfinder.org).

## FACES OF PATHFINDER

Melissa Fortson has joined the Pathfinder staff as its disability resource specialist. A *magna cum laude* graduate of The University of the South (Sewanee), Melissa is certified as an Information and Resource Specialist by the Alliance of Information and Referral Systems (AIRS). As Pathfinder's resource specialist, she is responsible for activities associated with the Tennessee Disability Services and Supports Directory and maintains the Pathfinder database and Web site, which include over 1600 agencies and 4000 Tennessee and national agencies. Immediately prior to joining Pathfinder, she served as the information & resource specialist at the Greater Nashville Area Agency on Aging & Disability (GNAAAD).



Melissa joins Christina Jensen, part-time social work student, Mayra Yu Morales, part-time disability community outreach worker, Claudia Avila-Lopez, bilingual social worker, and Carole Moore-Slater, program director.

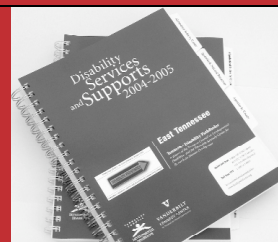
## FOR FURTHER INFORMATION:

Tennessee Disability Pathfinder  
(615) 322-8529 (Nashville area)  
(800) 640-4636 (toll-free)  
(800) 273-9595 (TTY)  
[www.familypathfinder.org](http://www.familypathfinder.org)  
[tnpathfinder@vanderbilt.org](mailto:tnpathfinder@vanderbilt.org)

## 2004-2005 DIRECTORY DISCOUNT: NOW ONLY \$15

2004-2005 *Tennessee Disability Services & Supports Directory*, published by the Tennessee Disability Pathfinder Office, is a source of information regarding state and local programs and services. The newest edi-

tion is available by geographic region (East, Middle, and West Tennessee). Order forms are available online at <http://kc.vanderbilt.edu/devents/order.html>



*Continued from page 3*

but they couldn't fix an emergency exit safe enough for us to get out of in case of a fire. So we had to stay at Harris-Hillman School for a few months of that school year until they found a school for us to go to. That's where I had my first experience with advocacy, of fighting for something that I believed in.

Our class was last to go to lunch. The lunch room ran out of food before our turn. I had physical therapy before lunch, which always made me late. Many days all I had was cottage cheese and skim milk! So my friend Leanne and I wrote a letter complaining of the situation in the school newspaper, but the teacher over the newspaper wouldn't publish it. Luckily, our teacher talked to us about the situation. That's the first time I felt like adults really listened to me. That's when I learned that I could do the same thing as the rest of the children, just in different ways.

In sixth grade, I moved to Sumner County where they had just three students with disabilities in the regular school system, and one of them was homebound. I graduated in 1985 in the top third of my class. I have attended college at MTSU twice. I studied social work the first time, and now, since 2000, I have been working on a bachelor's degree in University Studies.

I might not have been as happy as I am now. Another girl I know who has CP—but not as severely as I do—once told me that fighting for extra rights for disabled people gives us a bad reputation as crybabies and troublemakers. She also said it was a waste of my time to fight for the rights of the disabled, because we should live under the same rules as everybody else. Making everything accessible for us would be too costly and a waste of money that could be used to help children and women who need it to live. She also said I was letting my disability run my life, by belonging to disability organizations and wanting to do my internships with disability groups. She thought I should be living in the real world with normal people.

In her mind, I should be ashamed of how I eat or laugh in public. She said I should go back

home or to a nursing home and just watch television for the rest of my life and stop wasting taxpayers' money on my worthless life.

I thought to myself, if it was not for people like me she'd probably be sitting in her home by herself, living her life in isolation! She was in my face giving advice. I took it as long as I could. Finally I called her not so nice a name, and she ran to tell my caregiver (who was her best friend) that I should be punished because I was rude and mean to her. Never mind it was my apartment that I paid for with my own money!

My caregiver acted like she owned it, and like I was a child. She took my TV and computer away for a week, and told me her friend could come to my house if I liked it or not.

I think most people think my communication device is just a machine—instead of my voice. One caregiver thought it was a waste of her money to pay five thousand dollars for it when I could use a cheap alphabet board to express my dumb ideas. She said people with disabilities rely on expensive technology to do what God doesn't want us to do. I said, what if somebody took her mouth and her legs? She said God made her superior to me. That hurt me because I think she was wrong. I think that God made technology to help people like me.

Some of my caregivers thought it was a good punishment for me to take my communication device away. I felt like they used that to control me, to do what they wanted me to do. That made me feel like a child, and isolated. They thought they had the right to do whatever they wanted to. But it was my fault for not fighting back. I don't know why I didn't fight back, because it was very unlike me.

I am still learning how to keep that line between being the boss and a friend. The other day I was between meetings, and a friend let me stay in her office. My aide used my cell phone to call her friends without asking me, and talked about things I would be embarrassed to talk about in public, or in front of my boss.

When my last caregiver wasn't mad at me, she would tell me that she loved me as a sister. But she wanted to pick my friends and have her values. She also wanted to have her friends over to my apartment. When I fussed about it, she would say that my mother had put her in charge of me, and there was nothing I could do about it.

She kept telling me that she was my only friend. When she told me that every day for several weeks, I was beginning to believe it. I think she was trying to get me to be dependent on her. Afterward she left me alone in a hotel room in California, and my friend Leanne found me after a day of just water, pudding for food, and television for company. I found out who my real friends are.

After I moved home again I had a few caregivers who did what I wanted. We became friends, but they always treated me like I was the boss. I thought I had died and gone to heaven.

I found out it is more important being a boss than a friend. So remember: Don't let them take over your life. If they don't like Elton John, tell them it is your life and they should buy some earplugs!

Some of the people I know who have cerebral palsy think it is a curse, but I think it is a blessing. If I didn't have CP, there's no way I could have done all of the great things I've gotten to do—like participate in the longest sit-in in the country and doing Partners. If I didn't have CP, I certainly wouldn't have met any of my cool friends I have now. And if I didn't have a disability, I wouldn't be the same me.

*Besides being an effective advocate for herself and others, Lorri Mabry is a graduate of the 2000-01 Partners in Policymaking™ class, serves on several community boards and committees, and is actively involved with planning for the Tennessee Disability MegaConference.*

# TWO NEW TENNESSEE CENTERS FOR INDEPENDENT LIVING

By Melissa Smith

THE STATEWIDE INDEPENDENT LIVING COUNCIL OF TENNESSEE (SILCTN) RECENTLY ANNOUNCED EFFORTS TO WARD THE FORMATION OF TWO NEW CENTERS FOR INDEPENDENT LIVING (CILs), BRINGING THE TOTAL NUMBER OF CILs IN TENNESSEE TO SEVEN. ONE WILL SERVE THE NORTHEAST TENNESSEE AREA AND THE OTHER WILL SERVE NORTHERN (MIDDLE) TENNESSEE.

Community members within each of the two regions have been working together through grassroots efforts to start a CIL that will cover the following counties:

- CIL-NET (Center for Independent Living of Northeast Tennessee), serving Sullivan, Johnson, Carter, Washington, Unicoi, Green, Hawkins, Hancock, Claiborne, Grainer, Hamblen and Cocke Counties.
- TARP Inc. (Training, Advocacy, Referral, and Peer Support, Inc.), serving Montgomery, Robertson, Stewart, Houston, Dickson, Humphrey's, Benton, Henry, and Weakley Counties.

Each CIL is a non-residential, private, not-for-profit organization that operates independently from the other CILs throughout the State. Each has its own board of directors and organizational goals; however, all of the CILs seek to maximize the independence of individuals with disabilities and the accessibility of the communities in which they operate. CILs operate as separate entities from SILCTN and are funded, in part, by the Department of Education, Rehabilitation Services Administration's Independent Living Branch, to provide, among other things, the following core services:

- Advocacy
- Independent living skills training
- Information and referral
- Peer support

In addition to the four mandatory core services, each CIL works toward learning what other services are needed in their communities and searches for ways to develop these areas and obtain additional

funding to provide and sustain them.

The five established CILs are in Chattanooga (Tri-State Resource & Advocacy Corporation), Jackson (Jackson Center for Independent Living), Knoxville (Disability Resource Center), Memphis (Memphis Center for Independent Living) and Nashville (Center for Independent Living of Middle Tennessee). To access a link to each of the existing CILs Web sites, go to [www.tnsilc.org](http://www.tnsilc.org)

## WHO IS THE STATEWIDE INDEPENDENT LIVING COUNCIL?

The SILCTN is a not-for-profit, 501(c)3 organization established pursuant to the Rehabilitation Act of 1973, as amended. It is SILC's mission to promote, support, and provide independent living services that are consumer controlled by and for a cross-disability population of all ages. Such services are non-residential and are to be provided within an integrated, fully inclusive setting to ensure the maximum leadership, empowerment and independence of individuals with disabilities.

The SILCTN is responsible for the development of a State Plan for Independent Living (SPIL) in partnership with the Tennessee Division of Rehabilitation Services. Every three years, a SPIL is submitted for approval to the Rehabilitation Services Administration of the U.S. Department of Education in order that the SILCTN continue to receive funding for its programs.

The goals of the SPIL promote systems change that furthers the inclusion and independence of persons with disabilities. The three primary goals of the current SPIL

are to: (1) develop and support a network of centers for independent living across Tennessee; (2) promote independent living of persons with disabilities by supporting programs that empower people to make decisions contributing to self sufficiency; and (3) effect community change in order to increase the availability and improve the quality of statewide systems, programs, and services for people with disabilities.

Members of the Statewide Independent Living Council are very glad to be part of the development of the two new CILs in Tennessee and look forward to assisting CIL-NET and TARP in the coming months.

For more information on the SILCTN or existing CILs, contact the Statewide Independent Living Council at 615-255-0283 or go to [www.tnsilc.org](http://www.tnsilc.org).

Members of the SILCTN board are:

CASSANDRA BUCHANAN NASHVILLE,  
LILLIAN BURCH, KNOXVILLE  
SAMUEL COLE NASHVILLE,  
DEBORAH CUNNINGHAM, MEMPHIS  
SHARON GOOD, GRAY  
PAUL JONES, MARTIN  
VALERIE ROBERTS, KNOXVILLE  
MICHAEL SEAY, MEMPHIS  
SHIRLEY SHEA, NASHVILLE  
TONY SMITH, MCMINNVILLE  
EDWARD WILHITE ROCK ISLAND,  
WANDAWILLIS, NASHVILLE

*Melissa Smith is the former executive director of the Statewide Independent Living Council of Tennessee and is assistant director of Disability Services, Opportunity Development Center at Vanderbilt University.*

## TENNESSEE SPOTLIGHT

**Elizabeth Bishop**, community education director/dissemination coordinator at the Boling Center for Developmental Disabilities, is the new chair of the National Community Education Director's Council of the Association of University Centers on Disabilities.

**Andrea Cooper** was named assistant commissioner for the Division of Rehabilitation Services within the Tennessee Department of Human Services (DHS) in July.

"I am eager to lead the Division in its provision of efficient and effective services for our rehabilitation clients. . . . A large part of our effectiveness hinges on our ability to equip clients with the skills that will enable them to handle the responsibility that goes with their right to self-direction."

DHS Commissioner Virginia Lodge commented that she is confident that with Ms. Cooper's unique perspective and management skills "we'll be able to build upon this already excellent program."

Ms. Cooper has had quadriplegia since 1997 due to a spinal cord injury. She returned to the workforce through the assistance of vocational rehabilitation in 2004. She comes to the position of assistant commissioner with a B.A. in English from Indiana University and a law degree from Vanderbilt University. Ms. Cooper's professional experience includes being house counsel for insurance giant American General and staff attorney for the Tennessee Department of Finance and Administration. Her most recent position was house legal counsel for Permobil, Inc., a powered wheelchair manufacturer located in Wilson County. Ms. Cooper is also the chairperson of the Tennessee Council on Developmental Disabilities.

**Centerstone**, a behavioral healthcare organization serving Middle Tennessee, has received grants totaling nearly \$8,000 from the Tennessee Arts Commission and Metropolitan Nashville Arts Commission. The funds will be used by the Middle Tennessee Mental Health and Substance Abuse Coalition to create a program for people with mental illness and substance abuse disorders to express their creativity. Local artists will give workshops and provide curatorial assistance. Consumer artwork will be exhibited at various venues through the end of the year and in 2006.

**Martine Hobson** and **Lori Siegal**, of Memphis, were congratulated by the Down Syndrome Association of the Mid-South for their election to the board of the National Down Syndrome Congress held in Anaheim, California, in July. Ms. Hobson was elected by the general membership to a three-year term and Ms. Siegal was elected by Self-Advocates from across the country to fill a three-year slot on the board. Ms. Hobson is the mother of a 20-year-old daughter, Laurie, who has Down syndrome. Ms. Siegal is a 25-year-old self-advocate who has Down syndrome. The National Down Syndrome Congress is the oldest national organization serving as a support network for individuals with Down syndrome and their families.

**Jordan Huffman**, who has Down syndrome, had a great year playing baseball with the Collierville Youth Athletic Association, scoring four runs and many assists. This picture first appeared in June in the Collierville Herald with the following caption: "Jordan Huffman fires up his Collierville Youth Athletic Association Ranger baseball team as he heads to the plate while Coach Rob Murphy cheers him on. The spirit of CYAA is captured in the enthusiasm, sportsmanship and dedication shown in this photo." Jordan is the son of Kathryn Huffman, '03 graduate of the Council's Partners in Policymaking™ program.



**Pat Levitt**, director of the Vanderbilt Kennedy Center for Research on Human Development, received the 2005 Research Champion Award from the Autism Society of America (ASA). The award was presented in July, during the ASA's annual meeting here in Nashville at the Convention Center. Dr. Levitt's genetics and basic research studies focus on understanding the basis of autism and other neurodevelopmental and neuropsychiatric disorders, and how genes and the environment together influence development.

**Matthew Moore** is manager of the freshman football team at Brentwood High School and was a candidate for freshman representative to the Court of the Homecoming King and Queen for 2005. Matthew, who has Down syndrome, is the son of Richard Moore, a representative from the Mid-Cumberland Development District to the Council on Developmental Disabilities, and Sheila Moore, director of the Down Syndrome Association of Middle Tennessee, and brother to Katie Moore.



**Ms. Wheelchair Tennessee** is not a beauty contest, but a competition, started in 1996, to select the most accomplished and articulate spokesperson for persons with disabilities across the State of Tennessee. Contestants take part in a one-day program, including workshops and a talent show. Ms. Wheelchair Tennessee is charged with a continuing effort to educate the public regarding the dignity, productivity, and basic values of people with disabilities, and will ultimately represent Tennessee at the Ms. Wheelchair America Program. This year's winners truly represent the entire State. They are: Ms. Wheelchair TN **Shana Danielle Donnelly**, 25, from Upper East Tennessee; Junior Ms. Wheelchair TN **Brittany Carter**, a high school senior and YLF 2005 graduate from West Tennessee; and Little Miss Wheelchair TN **Jessica Duke**, a 9-year-old fourth-grader from Middle Tennessee.

**Patricia Nunally** is the mother of a child with a disability and has taken her advocacy for all children with disabilities to the airwaves. Ms. Nunally is the creator and executive producer of a new talk show, *On Cable Tonite*, carried by Time Warner Cable on Public Access Channel 17 in Memphis. The first show aired August 23, 2005, at 6:30 pm. Ms. Nunally has a six-month agreement with Time Warner Cable.

**Sarah Philpott**, of Chattanooga, who is a graduate of the Council's 2001-02 Partners in Policymaking™ class, is attending Hiwassee College in Madisonville as a special student and is living on campus. Ms. Philpott, at 28, is the second adult with Down syndrome to attend Hiwassee.

**Lizzy Solomon**, youth entrepreneur, has taken the top prize in her age group for the second consecutive year at the CEO (Children's Entrepreneurial Opportunities) Academy Awards luncheon, held at the Doubletree Hotel on July 30. Lizzy again will travel to Milwaukee to compete on a national level with her greeting card business, *Lizzy's Line*, which sells cards with sign language and other positive images of disability. Lizzy, who has cerebral palsy and is a 7th grader at J. T. Moore Middle School, won the top national award last year. Lizzy is the daughter of Council staff person, Ned Andrew Solomon, and Amy Harris-Solomon, director of the Easter Seals McWhorter Family Children's Center.

On September 29th, federal Administration on Developmental Disabilities Commissioner Pat Morrissey announced that the **Vanderbilt Kennedy Center for Research on Human Development** has won a \$2.5 million, five-year grant and designation as a University Center for Excellence on Developmental Disabilities Education, Research and Service. There are just 61 such centers nationwide. Vanderbilt's designation, along with the University of Tennessee Boling Center for Developmental Disabilities existing designation, makes Tennessee one of just a handful of states to host two of these centers. The Vanderbilt center of excellence will be directed by Elisabeth Dykens, professor of psychology and human development and the Vanderbilt Kennedy Center's associate director. The center will work in partnership with Tennessee's other ADD partners, the Boling Center for Developmental Disabilities, the Tennessee Council on Developmental Disabilities and the Disability Law & Advocacy Center of Tennessee (Formerly Tennessee Protection & Advocacy, Inc.).



## WHAT IS THE TENNESSEE YOUTH LEADERSHIP FORUM?

A 4-day exciting, informative, fun and **FREE** leadership and self-advocacy training program for rising 10th, 11th and 12th graders with disabilities from across the State of Tennessee

### WHERE AND WHEN DOES IT TAKE PLACE?

June 5-8, 2006

On Vanderbilt University campus

### WHAT WILL THE STUDENTS DO?

Engage in small and large group discussions

Complete a personal leadership plan

Attend sessions on leadership, assistive technology, living on one's own, reaching career goals, and college resources for students with disabilities

Tour the Capitol and meet with a Legislator

Participate in a photography workshop and a talent show

### HOW DO STUDENTS APPLY?

Contact: Ned Andrew Solomon

Director, Partners in Policymaking™

Phone: (615) 532-6556

E-mail: ned.solomon@state.tn.us

**DEADLINE FOR APPLICATIONS IS FEBRUARY 28, 2006**



# HISPANIC DISABILITY OUTREACH

## By Traci Fleischman

Tennessee Disability Pathfinder's Project Conexión connects the unserved and underserved Hispanic community of Metropolitan Nashville and Davidson County to disability resources, thanks to a partnership among the Vanderbilt Kennedy Center, the Tennessee Council on Developmental Disabilities, and the Woodbine Community Organization.

"Conexión builds on the Tennessee Disability Pathfinder program, which offers a Web site in Spanish and a bilingual social worker," explained Elise McMillan, project director and director of community outreach for the Vanderbilt Kennedy Center. "We were able to develop this model program as part of a grant from the Administration on Developmental Disabilities to the Tennessee Council on Developmental Disabilities."

Individuals from the Nashville community and surrounding areas come to the Woodbine Community Center to meet with the Pathfinder staff, Mayra Yu-Morales, a disability resource worker, and Claudia

Avila-Lopez, Pathfinder's bilingual social worker. Individuals and families are interviewed and referred to appropriate community resources.

"Mayra has to be creative when sending a person to an agency because there are not a lot of resources in the surrounding areas that can help. One of the biggest challenges is trying to get individuals with disabilities more involved and aware of the resources that are

available. Families come into the Woodbine Community Center needing legal, housing, financial, and health care assistance. Each case is unique," explained Ms. Avila-Lopez.

Ms. Yu-Morales is very involved in the Woodbine community—she lives, works, and volunteers in the neighborhood. She is originally from Mexico City and after moving to the U.S., she became a nurse's assistant and worked closely with individuals with disabilities. Last year she received an injury that allowed her to gain another perspective.

"I could see what patients [in particular, Hispanic patients] had to go through. People with disabilities feel more confident and at ease when approaching me because of my own experience—we now have a connection. I can talk to people, agencies, and public workers and tell them that I understand. I have been in the patient's place as a person with a disability, and I have been on the medical side of it as well," stated Ms. Yu-Morales.

A prime example of the magnitude of the

impact that Pathfinder's Project Conexión has on the Hispanic community is the story of Simplicio Guerrero, a father who came in to see Ms. Yu-Morales at the Woodbine Community Center. He told her about his son, who is in his mid-40s, and was diagnosed with polio as a child; he is blind and uses a wheelchair.

"They came asking us for help finding a wheelchair because his current wheelchair

was falling apart," explained Ms. Yu-Morales. Ms. Avila-Lopez and Ms. Yu-Morales went to the client's home and assessed the situation. Ms. Yu-Morales quickly got in touch with Greg Cox at United Cerebral Palsy of Middle Tennessee (UCP), and they donated a custom-fitted recliner wheelchair, a shower chair, and other necessary items.

"The family was so excited. They wanted to give a donation to the UCP to show their thankfulness," stated Ms. Yu-Morales. "The family continues to stop by Woodbine and will bring me a soda just to show their sincere gratitude to me and the Project. They are happy and thankful, and it is all because of this Project and the excellent resources that are now available. That is only one of the many stories of the Woodbine Community Organization," explained Ms. Yu-Morales.

Pathfinder social worker, Ms. Avila-Lopez, was born in Chihuahua, Mexico, and moved to Midland, Texas, 12 years later. Her primary role is to develop Pathfinder's Hispanic outreach program around the state, including Project Conexión. Ms. Avila-Lopez joins Ms. Yu-Morales at the Woodbine Community Center once a week.

On April 20, Ms. Avila-Lopez and Ms. Yu-Morales hosted the first conference for agencies that work within the Hispanic community in the Nashville area. "The conference far exceeded our expectations. Forty bilingual professionals learned how to better communicate with individuals with disabilities and with service providers," explained Ms. Avila-Lopez. Conference attendees included, among others, the Mental Health Association of Middle Tennessee, Catholic Charities of Tennessee, Metro Social Services, Tennessee Protection and Advocacy [now Disability Law & Advocacy Center of Tennessee], Tennessee Infant Parent Services, Outlook Nashville, and the Knowles Senior Center.



MAYRA YU-MORALES AND CLAUDIA AVILA-LOPEZ, STAFF FOR PATHFINDER HISPANIC DISABILITY OUTREACH

# CAMP HICKORY WOOD 2005

By Rachel Heitmann

Another season of Traumatic Brain Injury camping has come and gone. This year, the Traumatic Brain Injury Program sponsored an adult/youth weekend camp in May and two week-long camps in July, one for youth and one for adults. All three sessions were extremely enjoyable, with campers looking forward to next year.

Camp Hickory Wood was developed by the Tennessee Traumatic Brain Injury Program, in collaboration with Easter Seals, and is dedicated to providing quality summer camping experiences for people who have sustained brain injuries. Nestled between the banks of Old Hickory Lake and surrounded by protective woods, the camp offers great outdoor fun. Campers enjoy a variety of activities, including swimming, boat rides, arts

and crafts, card games, and movies. Camp activities are designed to provide challenges, build confidence, foster new friendships, and most importantly, be fun.

This year, the wet weather forced campers to find indoor activities on several days. Campers had fun playing pool, tie dying T-shirts, and watching movies, in addition to an Uno tournament and a talent show. Even with all of these activities to choose from, one camper said "just being with my friends" was what she liked the most.

Several of the campers said their favorite event of the week was the dance held the last night of camp. This was a time to connect with old friends or exchange phone numbers with new friends before returning home. With camp coming to an end, a wide array of emotions filled the room during the dance. Some campers were excited about meeting new friends and keeping in touch with them. Others felt a sense of sadness that the experience was coming to an end. One of the campers said, "This is the only time I'm

around people that understand me." Other campers agreed, and this sense of belonging and understanding of each other is what keeps campers coming back year after year.

For more information about Camp Hickory Wood, contact the Traumatic Brain Injury Program at 1-800-882-0611.

*Rachel Heitmann is the health educator with the Tennessee Traumatic Brain Injury Program.*



Mitch Harris, in boat, with camp counselors.  
Photo Credit: Terry Moore

With the collaboration between the Vanderbilt Kennedy Center and the Woodbine Community Center, disability resource materials are identified, and staff are developing and disseminating bilingual information and referral resources to Spanish-speaking Tennesseans. The partners bring awareness, information, and referral of disability information to Hispanics through the Woodbine community and provide a model that can be used in other communities and states.

Wanda Willis, executive director of the Tennessee Council on Developmental Disabilities, summarized the initiative's impact: "Project Conexión and our partnership with the Vanderbilt Kennedy Center has accomplished more toward connecting disability advocates and systems to the Hispanic community than anything else the Council has sponsored."

*Traci Fleishman is a writer in the Vanderbilt Kennedy Center's Communications office.*

This article appeared originally in *Discovery* and is reprinted here with the Kennedy Center's permission.

## CONEXIÓN

El proyecto conexión del Disability Pathfinder es un programa de información y referencia para individuos con discapacidades que está localizado en el Centro Comunitario de Woodbine. La meta del proyecto es ayudar a las personas hispanas con discapacidades y a sus familias incrementando el conocimiento de los servicios disponibles mientras mejoramos el acceso a programas existentes. Los objetivos incluyen: (a) Ayudar a individuos a entender los sistemas de discapacidades y asegurar servicios comunitarios disponibles, (b) crear recursos de información y referencia en agencias locales para conectar a individuos hispanos a recursos que ya existen, y (c) proveer entrenamiento técnico de discapacidades en la comunidad. Para más información llame a Mayra Yu-Morales en Woodbine (615) 850-3448 o a Claudia Avila-Lopez en la oficina del Disability Pathfinder (615) 322-7830.

# PROJECT OPPORTUNITY

## By Sara Ezell

In July of this year, Vanderbilt Children's Hospital received a startup grant from the Division of Rehabilitation Services (DRS) to develop and implement Project Opportunity, a dynamic new initiative to provide job experience and jobs to high school seniors with developmental disabilities. Modeled after a highly successful program at Cincinnati Children's Hospital Medical Center, Project Opportunity represents a partnership among Vanderbilt University Medical Center, the Division of Rehabilitation Services, the Department of Human Services, Community Options, Inc. (which provides job coaching and job development expertise) and the Williamson County School System. Williamson County Schools already has a grant with DRS to provide transportation to community based job training sites, thus it was a natural fit to pilot the program using students from Williamson County.

Terrell Smith, director of Patient/Family Centered Care for Vanderbilt Hospital, spearheaded this program at Vanderbilt after seeing the Cincinnati program in action and understanding the business need of the hospital to have qualified, dependable employees. In August, the staff (small but mighty!) was hired. Sara Ezell is the program coordinator and is an employee of Vanderbilt Children's Hospital. Her responsibilities include: promoting the program in the Medical Center and in the community, developing and maintaining supportive relationships with departments to assure positive worksite rotations, and securing ongoing funding so that the program can continue and expand in the years to come. Michelle Halman is the project coordinator and is an employee of Community Options, Inc. Her responsibilities include: identifying tasks that would be appropriate for the students, conducting job analyses to facilitate training of the tasks, and overseeing job coaching

for each participant. Job coaches, who will also be employees of Community Options, are currently being interviewed.

Under the guidelines of the grant, students participating in the pilot program of Project Opportunity must fall under the following criteria:

- BE 18 TO 22 YEARS OLD
- HAVE COMPLETED HIGH SCHOOL CREDITS
- AGREE THAT THIS WILL BE THE LAST YEAR OF STUDENT SERVICES, AND WILL RECEIVE SPECIAL EDUCATION DIPLOMA AT THE END OF THE SCHOOL YEAR
- HAVE INDEPENDENT PERSONAL HYGIENE AND GROOMING SKILLS
- HAVE INDEPENDENT TOILETING AND FEEDING SKILLS
- HAVE THE DESIRE TO WORK
- MAINTAIN APPROPRIATE BEHAVIOR IN THE WORKPLACE
- HAVE APPROPRIATE SOCIAL SKILLS
- HAVE ABILITY TO TAKE DIRECTION AND CHANGE BEHAVIOR
- BE ABLE TO COMMUNICATE EFFECTIVELY
- HAVE AN INTEREST IN WORKING IN A HEALTHCARE OR BUSINESS SETTING
- HAVE A DESIRE TO EXPLORE TRANSPORTATION OPTIONS, AND TO BE TRAINED TO TRAVEL INDEPENDENTLY TO WORK
- HAVE PREVIOUS EXPERIENCE IN A WORK ENVIRONMENT (INCLUDING SCHOOL, VOLUNTEER, AND PAID WORK)
- ABILITY TO PASS DRUG SCREEN, FELONY CHECK, AND HAVE IMMUNIZATIONS UP TO DATE
- HAVE THIRD-GRADE READING AND MATH SKILLS

On October 3 five students began working. Report to their home schools for approximately one hour in the mornings, and arrive at the hospital via transportation arranged through DRS and Williamson County Schools at about 9:30 a.m. Students spend one hour having classroom instruction conducted by the Project Opportunity staff (and guest presenters, such as Human Resource representatives, hospital administrators and Vocational Rehabilitation counselors) regarding workplace behavior, employability skills, job search strategies and training on the particular job rotations. After this classroom time, students report to their job rotation with a member of the Project Opportunity staff. Each Project Opportunity participant will have two to four unpaid work-site rotations during the school year to experience various types of jobs. Before leaving the hospital at approximately 1:30

p.m., students gather in the classroom for discussion and debriefing about the positives and negatives of the day.

Ms. Ezell and Ms. Halman have identified several appropriate job rotations at Children's Hospital. One rotation is the distribution of stuffed animals to each patient floor, which includes skills of inventory, stocking, navigating the hospital, and elementary math (computing the total number delivered). Another rotation is a great deal more complicated: stocking nurse supplies on the neonatal unit. This rotation includes a detailed inventory, identifying and sorting materials with somewhat subtle differences, and data entry. Using a digital camera, printer, and some creativity, these tasks have been detailed in notebooks for the students to use on the rotations and in the classroom. The goal of the rotations is to provide varied experiences for the students in the hopes of identifying skill areas and preferences so that future job searches can be more directed and meaningful.

Students graduating from Project Opportunity will understand the value of working and develop pride in their workplace and in themselves. Following in the footsteps of Cincinnati Children's Hospital, Project Opportunity will use the foundation of this pilot year to expand next year to include adults with disabilities and students from other counties, and, ultimately, other job sites at Vanderbilt Medical Center and other community businesses. Project Opportunity seeks to bridge the gap between the need for qualified employees and the need of individuals with disabilities for jobs in a way that is beneficial, profitable, and successful.

Participants will receive education and on-the-job training for positions that are adapted to meet the participants' developmental and functional abilities. Throughout their experience in the program, the students will be provided ongoing job coaching to ensure their continued success at Vanderbilt on an extended basis.

*Sara Ezell is program coordinator for Project Opportunity at Monroe Carell Jr. Children's Hospital at Vanderbilt University.*

# ON MY OWN TERMS: MY JOURNEY WITH ASPERGER'S, by Robert Sanders, Jr.

A Book Review by Gina Lynch

Robert S. Sanders, Jr.'s book, *On My Own Terms: My Journey with Asperger's*, is a fascinating and insightful journey into the mind of an adult with Asperger's Syndrome. We have learned a lot about autism (Asperger's is a diagnosis on the autism spectrum) from the first-hand accounts of folks like Temple Grandin, Stephen Shore, and Donna Williams. Mr. Sanders adds a brilliant facet to this understanding. While not always an easy read, the book is an important addition to the autobiographical literature that we have from folks affected by autism and Asperger's. It is a must read for those interested in this particular diagnosis, as well as for anyone interested in the workings of the human mind.

*On My Own Terms* follows Mr. Sanders's life from his earliest childhood memories through grade school, college, his brief employment as an engineer, the books he writes, and his vast travels around the globe. Sprinkled throughout the narrative are heartbreaking anecdotes about struggles with maintaining friendships, the one aspect of having Asperger's that causes continuous disappointment. He writes candidly about his experiences in school, including episodes of abuse at the hands of teachers, as well as memories of successful classroom inclusion. Mr. Sanders offers many insights into why he reacted the ways he did to the folks around him, and leaves clues as to what should have been done differently.

Frankly, this section of the book meant the most to me as a parent of a young child with autism. I read and re-read it in an attempt to expand my understanding of what might be going on in my son's head. However, later sections on special interests, interactions with family members, and employment were quite perceptive as well. Gaining such insights is an incredible benefit to those who are trying to create "real lives" for those on the autism spectrum.

A word of warning might be appropriate here: the author frequently jumps from thought to thought without much in the way of transition. A section about traveling is interrupted by a paragraph about global warming. An anecdote about making friends awkwardly segues into a tirade about smoking. These brief lapses in linear story-telling made for a challenging read but, as the title of the book indicates, Mr. Sanders lives—and apparently writes—on his own terms. Still, the book's gifts are numerous.

Families of tiny babies will often catch a smile and ask one another, "I wonder what s/he is thinking." That question seems to endure for folks on both sides of the autism diagnosis. Mr. Sanders feels his differences from the people around him distinctly enough to wonder whether he was born on the wrong planet or into a parallel universe to where he belongs. To a family member, doctor, teacher, or member of the community trying to understand why someone with autism reacts the way that they do, Mr. Sanders offers this insight: "Asperger's syndrome is not an illness. It is merely a different template for living. Those who have Asperger's also have a different set of codes to work with as they adapt themselves to life's situations."

Mr. Sanders offers us a guidebook for translating some of those codes so that barriers of communication can be overcome and acceptance of differences can be increased. If the conversations the book has inspired among my family and friends are any indication of the impact of Mr. Sanders's writing, he has achieved his goal.

*Gina Lynch is a guest contributor to Breaking Ground. She is the founder of Untangle Autism!, a Web site for parents of children with new autism diagnoses. Ms. Lynch is a graduate of the 2003-2004 Partners in Policymaking™ class and the secretary of the Board of The Arc of Tennessee.*

## A NOTE FROM A FATHER

By Robert S. Sanders, Sr.

*My son, Robert, was a healthy, pleasant, responsive affectionate toddler until, at age 2-1/2, he drifted away from us, into the apparent shell of autism.*

*A significant event occurred in our family some 37 years ago. That involved a silver moon, a barnyard, and the onset of speech conversation with our son's first two words: "Da moon." Under the silver moon, I had carried Robert across the barnyard to check on a new lamb in the sheep shed. Lambing time was with us; one newborn was with his mother near a heat lamp. It was quite cold for April.*

*On our return across the barnyard, Robert looked toward the sky in the northwest dominated by a huge beautiful moon. He raised an arm, pointed northwest and announced "Da moon." Robert must have been startled by my tears of joy, enhanced by my wife's waiting in the kitchen. We still remember the event well.*

*Robert's speech improved from then on. He did very well in school, and has even become bilingual, as he is fluent in Spanish. His subsequent writing skills have yielded several books, especially his autobiography about Asperger's syndrome in the autism spectrum, available in both English and Spanish.*



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